

I am writing to draw your attention to the difficulties currently experienced by a group of younger patients needing residential care currently only available in NSW in Nursing Homes.

For the last 8 years I have been working with persons affected by Huntington Disease. This is an adult onset inherited neurodegenerative disease for which there is no cure. It causes destruction of brain cells and results in physical, cognitive and emotional changes. All sufferers develop a subcortical dementia. The most common age of onset is between 35 and 50 years. The duration of the illness is approx. 20 years though with better care patients are living longer-25years. From our careful tracking of patients we know that patients spend approximately 10 years in the community and 10 years in residential care.

Therefore we are in the position of attempting to seek admission to Nursing Homes/ high level care for all our patients in the later stages of their illness. This Service is the specialist service for this illness in NSW. We have a 17 bed residential unit at Lottie Stewart Hospital at Dundas to which people from all over NSW seek admission. There are 15 permanent beds and 2 respite/admission beds. The permanent beds are kept for persons under 50 years but are by no means enough. The only alternative is to seek admission to Nursing home beds in Aged Care facilities.

The incidence of this illness is 6.5 cases per 100,000 of population giving an incidence in NSW of around 400 people at any one time. Of this number 300 people are known to this Service at any one time. Of these approx. 100 people are in care. The majority of these [90/105] are in Nursing Homes. The remainder are in Hostel/low level care. Two thirds of those in care are under 65 [75/105] Under 50 years there are 31/105.

Whilst there is a strong lobby group in the community who want to see no young person in a nursing home it should be remembered that admission to a NH is not a lifestyle choice of the aged. People are admitted to this care primarily because of their nursing care needs. It happens that the majority of people needing this care are aged but there are younger people who also need 24 hour supervised nursing care.

Currently funding for nursing home care comes through the Commonwealth Dept of Aging and Disability. Whilst the Commonwealth agrees to fund younger people if all other avenues to keep the young person out of aged care are exhausted, many Aged Care Assessment Teams refuse to assess younger people and many nursing homes refuse point blank to admit younger people. The critical factor should not be the age of the person but rather the need for high level nursing care.

In the view of this Service a solution would be to facilitate interested nursing homes to set up clusters of younger residents. The overall numbers of younger people needing this level of care would not be huge and would primarily consist of younger persons with chronic neurological conditions. The period of time spent in care is much longer than for aged persons but the numbers requiring this care are much smaller. By having clusters nursing expertise could be developed in caring for these conditions and social programmes and surroundings could be adapted to a younger clientele.

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